

Wednesday, 27 February 2019

ARRIVAL IN TUNIS

Thursday, 28 February 2019

Venue: Institut Pasteur de Tunis

08:30 – 09:00 | REGISTRATION

09:00 – 09:15 **Welcoming word and presentation of the rare disease day event**

Dr. Anis Ben Amor

University of Tunis El Manar, Tunisia & AGYA member

Dr. Olfa Messaoud

Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia & AGYA member

09:15 – 12:30 **Session 1: Raising awareness for health care professionals**

09:15 – 10:00 **Challenges related to the investigation of rare diseases in the region**

Prof. Sonia Abdelhak

Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

10:00 – 10:30 | COFFEE BREAK

10:30 – 11:30 **Clinical gene therapy for neurodegenerative diseases: Past, present, and future**

Prof. Nathalie Cartier

Université Paris-Sud, Université Paris-Saclay, Orsay, France

11:30 – 12:30 **Roundtable by various stakeholders on rare diseases**

Representatives of several Arab countries
Algeria, Egypt, Kuwait, Libya, Mauritania, Oman, Palestine, Sudan, Tunisia, UAE

12:30 – 14:00 | LUNCH BREAK

14:00 – 18:00 | SCIENTIFIC EXCURSION

Friday, 01 March 2019

Venue: Tunis Science City

09:00 – 17:00 **Session 2: Raising awareness for general public & civil society**

09:00 – 09:15 **Experience of the patient's support group 'Helping children with Xeroderma pigmentosum'**

Prof. Mohamed Zghal & Prof. Meriem Jones
Charles-Nicolle Hospital, Tunis, Tunisia

09:15 – 09:30 **Pour que nos anges ne perdent jamais le sourire**

Prof. Ichraf Kraoua
National Institute of Neurology Mongi-Ben Hamida, Tunis, Tunisia

09:30 – 10:00 | MUSICAL PIECES PERFORMED BY PATIENTS

10:00 – 10:15 **Activities of the 'Tunisian Association of Lysosomal Diseases'**

Mr. Mouadh Saaied
Tunisian Association of Lysosomal Diseases, Tunis, Tunisia

10:15 – 10:30 **Après 3 ans de sensibilisation sur les maladies rares, quels résultats en Tunisie?**

Dr. Mariem Ben Rekaya
Association REACT «La Recherche en Action», Tunis, Tunisia

10:30 – 11:00 | COFFEE BREAK

11:00 – 11:30 **Role of Tunis Science City in filling the gap between scientists and society**

Prof. Dorra Ghorbel
Tunis Science City, Tunis, Tunisia

11:30 – 12:00 **Patient's sessions (Success stories presented by patients)**
Ms. Abir Mhamdi: رحلة المرض, Ms. Hiba Hamzaoui, Ms. Nadia Jerbi & Parents of Angelman patients

12:00 – 12:30

Les modalités de prise en charge psychopédagogiques des élèves en difficultés scolaires: Les classes orthopédagogiques

Dr. Nouredine Elhadawi
Faculty of Humanities and Social Sciences of Tunis, Tunis University, Tunisia

12:30 – 14:00 | LUNCH BREAK

14:00 – 15:00 **Les boutiques des sciences: Un outil de la recherche participative. L'expérience de l'Institut Pasteur de Tunis**

Mr. Hichem Ben Hassine
Institut Pasteur de Tunis, Tunisia

15:00 – 16:00 **The voice of secondary school students for rare diseases (Twitter Project)**

Students of the Secondary School Gustave Flaubert, Tunis, Tunisia

16:00 – 17:00 **The history of music therapy**

Dr. Rami Chahin
Oldenburg University, Germany & AGYA member

17:00 – 18:30 | DINNER

18:30 – 20:00 | MUSICAL PERFORMANCE
by El Manar Conservatory Choir & Distribution of competition awards

Parallel session:

10:00 – 16:00 **Scientific workshops in the 'ADN pour tous' space in Tunis Science City**

Saturday, 02 March 2019

Venue: Institut Pasteur de Tunis

09:00 – 11:00 **Laboratory visits for secondary school teachers & students**

Molecular biology for genetic investigation of rare diseases

PhD student Rahma Mkaouar
Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

Genetic counselling and prenatal diagnosis

Prof. Mediha Trabelsi

Department of Hereditary and Congenital Diseases, Charles-Nicolle Hospital, Tunis, Tunisia

Genetics of neurosensory diseases

PhD student Rahma Mkaouer

Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

Genetics of cardiac diseases

PhD student Hager Jaouadi

Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

Rare forms of diabetes

PhD student Hamza Dallali

Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

Introduction to microbiota applications in rare diseases research

PhD student Meriem Fassatoui

Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

11:00 – 13:00

Scientific workshops in the

'ADN pour tous' space in Tunis Science City

DEPARTURE FROM TUNIS

Conference Venue

Institut Pasteur de Tunis

Address: 13, Place Pasteur, Tunis Belvédère, Tunis

Tunis Science City

Address: Rue La Cité des Sciences, Tunis 1004

Conference Organizers

Dr. Olfa Messaoud

Associate Professor at Institut Pasteur de Tunis, University of Tunis El Manar; Tunisia

Member of the Arab-German Young Academy of Sciences and Humanities (AGYA)

Dr. Ahmed Hegazy

Charité - Universitätsmedizin Berlin (CBF), Medical Department, Berlin, Germany

Member of the Arab-German Young Academy of Sciences and Humanities (AGYA)

In collaboration with

- Institut Pasteur de Tunis
- Tunis Science City
- Biomedical Genomics and Oncogenetics Laboratory
- Association REACT (La Recherche en Action)
- Association des Jeunes Chercheurs de l'Institut Pasteur de Tunis
- The EC H2020 Project InSPIRES
- Twelfth International Rare Disease Day

Contact: agya@bbaw.de

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ASSOCIATION
LA RECHERCHE
EN ACTION



LGBMO
Laboratoire de Génétique
Médicale et Oncogénétique
LR16IPT05



International AGYA Workshop

RAISING AWARENESS FOR RARE DISEASES

28 February - 02 March 2019

Tunis, Tunisia

Venues:

Institut Pasteur de Tunis (28 February & 2 March)
and Tunis Science City (1 March)